
South Korea's End-of-Life Care Decisions Act: Law for Better End-of-Life Care

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3.1 Introduction

On 8 January 2016, the National Assembly of the Republic of Korea passed the Act on Hospice and Palliative Care and Decisions on Life-Sustaining Treatment for Patients at the End of Life (ELDA). The Act's lengthy name arguably reflects the lengthy discussions in Korea about what constitutes acceptable end-of-life care. Although ELDA regulates end-of-life care in general, the legislators tried to narrow its potential application to the less-controversial condition of the "dying stage". This chapter begins with a description of end-of-life care, especially of those features of such care for which remedies are needed, and then moves on to a discussion of the law and ethics of end-of-life care in Korea. My focus is on end-of-life care decision-making rather than palliative care. The implications of ELDA are also discussed.

3.2 Background and History

3.2.1 *End-of-Life Decisions in the Courts*

Whilst ELDA 2016 represents the most significant legal development concerning end-of-life care in Korea, a full understanding of the trajectory of legal developments in this area requires that we first look at two landmark court cases that preceded the law and played an important role in motivating legal reform and changes to professional practice: the *Boramae Hospital* case (1998) and *Severance Hospital* case (2008). The latter was a civil lawsuit brought against the hospital concerned to force it to forgo life-sustaining treatment (LST), and the former was a criminal case against surgeons who had discharged a patient at his wife's request. The current legal regulation on end-of-life care decisions took its shape from the Supreme Court's decisions in these two cases. It is important to note that both cases pertained to the forgoing of LST, not to euthanasia.

3.2.1.1 Boramae Hospital Case

This case dealt with the legitimacy of surrogate decision-making when the withdrawal of LST and discharge would mean the death of the patient.¹ The issue contested at trial was how far the duty of care extends when a family insists upon a particular treatment. The physicians at Boramae Hospital had discharged the patient concerned, whose treatment was deemed to be LST, at the request of his wife. She had requested that her husband be discharged for economic reasons, that is, the financial burden of continued hospitalisation. The final verdict arrived on 24 June 2004. The Supreme Court found the surgeons guilty and sentenced them to one year and six months' imprisonment each. The court considered the surgeons to be guilty as accomplices to murder because they had (i) honoured the wife's request, which could not be regarded as an authoritative proxy decision and (ii) not taken proper measures to prevent an anticipated harm.

This judgment rang alarm bells amongst Korean doctors, who became concerned about the decision-making process at the end of life. The judgment confirmed that doctors' duty is this: treating a patient as an autonomous individual and considering his or her best interests under any circumstances.² However, confusion remained over whether every withdrawal of LST would result in liability or whether it was sufficient to consult all family members before any decision was made. Such confusion arose in part because there was no explicit written provision in Korean law. Further, most – but not all – decisions were made jointly by doctors and patients' family members on the assumption that the latter were conferred with the power to consider what is best for the patient, even though, as noted, there was no explicit legal provision for this.

Despite the serious ethical discussions on end-of-life care following the *Boramae Hospital* case, no formal mechanisms such as advance directives (ADs), durable power of attorney or clinical ethics consultation were implemented. Accordingly, many professional bodies were quick to develop guidelines to realise the spirit of the Supreme Court's decision. For example, the Korean Association of Medical Societies (KAMS) in 2002 developed guidelines on the forgoing of LST for dying patients that provide a clinical pathway resembling that of the American Medical

¹ K.H. Hahm and I. Lee, "Biomedical Ethics Policy in Korea: Characteristics and Historical Development" (2012) 27 *Journal of Korean Medical Science* S76.

² Korean Supreme Court Decision 2009 Do 995 delivered on 24 June 2004.

Association.³ Although the KAMS guidelines were developed and modified to fit the Korean context, they did little to improve the practice of end-of-life care planning, primarily because they have little binding force: there is no duty for doctors to follow the KAMS guidelines. Accordingly, doctors wanted a secure legal basis for following a patient's wishes, such as a clear exemption from liability. That desire stemmed from fear of the heavy penalty imposed by the Supreme Court in the *Boramae Hospital* case, not least the cancellation of the guilty doctors' medical licences.

It was not only the medical community that was concerned by the case; there were also concerns amongst bioethics activists that this decision would lead to euthanasia being legislated. The controversy continued for several years until the *Severance Hospital* case in 2009, which triggered the start of the ELDA legislation process.

3.2.1.2 Severance Hospital Case

This case concerned a request made by the family of a patient, a woman in her late 70s who was in a persistent vegetative state, to discontinue the medical treatment she was receiving. The family filed a lawsuit against Severance Hospital, which had refused to stop the treatment. The trial process in the case was unusually quick, with the Supreme Court ruling in 2009 that the withdrawal of LST could proceed based on the patient's presumed intent. The patient had once made a similar decision for her husband, and her preferences concerning LST were thus deemed by the court to be recognisable from her life attitudes. Notably, the Supreme Court imposed a limitation on the withdrawal of LST, ruling that "when it is recognised that a patient who has reached an irreversible stage of death exercises her right to self-determination on the ground of the constitutional rights of human dignity and right to pursue happiness, it is permissible to withdraw life-sustaining treatment".⁴

The *Severance Hospital* case was important in the sense that it was the first case in which a Korean court recognised a patient's right to refuse futile LST. Whilst the Supreme Court's decision apparently recognised patients' right to self-determination with respect to LST, we must take care not to interpret it as confirmation of the right to refuse life-saving treatment in general. There is a condition that must be fulfilled before a patient's

³ Committee on Reporting of Symposium on Euthanasia and Death with Dignity, Korean Association of Medical Societies, *KAMS Medical Ethics Guideline No. 1: On the Forgoing Life-Sustaining Treatment of the Dying Patient* (2002).

⁴ Korean Supreme Court Decision 2009 Da 17417 delivered on 21 May 2009.

treatment preferences can be executed: “he/she (should) have reached an irreversible stage”. This condition leaves little room for interpretation. Nevertheless, the spirit of the court’s decision in this case is that a patient’s right to refuse treatment should be institutionalised by legislation on end-of-life medical decision-making. Hence, the legislative process began.

3.2.2 *Consensus Building Process (2009–2012)*

The period prior to ELDA’s passage saw the Government set up various consultation bodies to facilitate social consensus-building in relation to end-of-life decision-making issues.⁵

3.2.2.1 Ministry of Health and Welfare’s Council on the Institutionalisation of Forgoing Life-Sustaining Treatments (2009–2010)

In 2009, the Ministry of Health and Welfare responded to the *Severance Hospital* case by organising the Council on the Institutionalisation of Forgoing Life-Sustaining Treatments. The council released its report in 2010. The minimal consensus the council members reached, which subsequently served as the starting block for a public engagement process, was as follows. The permissibility of LST withdrawal was to be restricted to “terminal patients” and to certain treatments. Nonetheless, the report recommended documenting end-of-life care preferences to make them explicit and establishing a review committee and conflict resolution mechanism. The consensus report can be summarised as follows:

- (i) The forgoing of LST is permissible only for terminal patients; patients in a persistent vegetative state are excluded unless they are in the terminal stage.
- (ii) The only treatments that can be withdrawn are extraordinary LSTs such as cardiopulmonary resuscitation (CPR) and artificial ventilation; hydration and nutrition should not be withdrawn.
- (iii) An “Advance Medical Directive (or Advance Medical Intention Documents)” should be written if a patient in the terminal stage wishes to express his or her preferences. Notably, an adult can write such a document after consulting with the attending physician following two weeks of mature deliberation.

⁵ M. Tanaka et al., “Forgoing Life-Sustaining Treatment – A Comparative Analysis of Regulations in Japan, Korea, Taiwan, and England” (2020) 21 *BMC Medical Ethics* 99.

- (iv) A National Terminal Care Review Committee under the Ministry of Health and Welfare and Hospital Ethics Committees in individual healthcare institutes should be established to facilitate the decision-making process in the end-of-life care context.

The council's 2010 report constituted baseline consensus amongst Koreans regardless of their attitudes towards the scope of end-of-life decisions. The National Bioethics Advisory Committee then joined the discussion by establishing a task force under the auspices of the National Bioethics Review Committee in 2013.

3.2.2.2 National Bioethics Review Committee's Task Force for Decision-Making about Futile LST and Recommendations of the National Bioethics Advisory Committee (2012)

In 2013, the National Bioethics Review Committee, established under the Korean Bioethics and Safety Act 2005, launched the Task Force for Decision-Making about Futile Life-Sustaining Treatment with the aim of giving the council's consensus concrete shape.⁶ The task force's final report discussed six issues: basic principles, potential patients, medical interventions, identifying a patient's preferences, social engagement and methods of institutionalisation.⁷ Although the National Bioethics Review Committee announced "agreed" recommendations for drafting an act, concerns remained over the potential abuse of end-of-life care decisions, and there were also demands for a more permissive law allowing patients to decide.

As for the basic principles of medical decision-making concerning LST, these were determined to be (i) a patient's right to an informed decision, (ii) respect for self-determination, and (iii) the provision of

⁶ There was some controversy about what futile LST should be called in Korean society around this time. Whilst the term "futile LST" or 无意义的 延命治疗, meaning "LST without any purpose", had been used previously, an influential member of the National Bioethics Review Committee, as well as a leading member of the hospice and palliative care movement, argued that this term should be replaced with the term "LS procedure" or 延命施术. He felt that removing the term "futile" would better reflect the societal view that futility was implied in the term "life-sustaining" and that it was important to replace the word "treatment" because of its connotation of benefiting patients. (See further M. Kim, "Context and Issues of 'National Bioethics Advisory Committee's Recommendation on Decision on Life-Sustaining Treatment': Emphasis on the Procedures of Task Force for Institutionalisation of Decision on Life-Sustaining Treatment" (2013) 11(3) *Research Institute for Healthcare Policy* 8.)

⁷ Y.S. Lee, "On the Life-Sustaining Treatment in Korea" (2012) 55(12) *Journal of Korean Medical Association* 1161.

hospice palliative care. The agreed recommendations limited the patients of concern to those in an irreversible condition with no hope of a cure and those with a rapidly aggravating condition that does not respond to treatment of the underlying disease. This narrow perspective can also be found in the treatments of concern, which are restricted to LSTs that require professional medical knowledge, skills and equipment, namely, extraordinary LST such as CPR, ventilator care, haemodialysis, anticancer chemotherapy and so forth. Patients can choose hospice palliative care. As for the method of identifying a patient's preferences, the recommendations prioritised a patient's explicit preferences over other means, such as a presumed will or surrogate decision-making. In the case of incompetency, documentation was recommended.

The task force's recommendations recognised the importance of the cultural and socioeconomic environments and the role of collaboration for improvement, although such recognition appeared to be largely symbolic, with very few follow-up actions apart from the establishment of a National End-of-Life Day and Ceremonial Day and social media and other campaigns promoting the concept of self-determination. The National Bioethics Review Committee's final recommendation was the institutionalisation of end-of-life care decisions through legislation.

3.2.3 Legislation

Before the successful legislative attempt in the 19th session of the National Assembly (2016), there had been seven bills drafted since 2006, namely, the Revision of the Medical Practice Act (2006), Hospice-Palliative Care Act (2008), Death with Dignity Act (2009), Law on the Right to a Natural Death at the End Stage of Life (2009) and three additional bills drafted during the 18th session and then again in the 19th. These draft bills, each of which had a different emphasis, were unsuccessful, perhaps because the public was unclear about the nature of futile treatment and there was insufficient societal pressure to engage with such issues more actively. It is noteworthy, however, that the Death with Dignity campaign subsequently took hold within Korean society.⁸ Owing to newspaper coverage of the *Severance Hospital* case and to the "dying well" campaign, the broader population gradually began to understand the importance of the right to

⁸ For more information, see Kakdang Social Welfare Foundation, www.kadec.or.kr/; see Korean Initiative for Advance Directive, www.sasilmoo.net. These two organisations were representatives of these activities.

self-determination and the possibility of dying free of any unnecessary medical interventions.

In 2015, a National Assembly member submitted a bill based on the recommendations of the National Bioethics Review Committee, and three other competing bills were also submitted. At a later stage of the legislative process, the bill on end-of-life decision-making and the bill on hospice palliative care were merged. In a sense, palliative care and end-of-life decision-making are closely related, and both had hitherto received less attention than they deserved. The new law came into force in July 2017, and its executive orders – a presidential decree and enforcement regulation – were legislated thereafter.⁹

As noted at the outset of this chapter, ELDA was passed on 8 January 2016. The Supreme Court had in the *Severance Hospital* case recommended legislation on the issues concerned in 2009, and thus the Act took many years to execute. ELDA's goal is "to secure the patient's best interest and to protect . . . human dignity and value by respecting self-determination" (Article 1 of ELDA). To achieve that goal, the Act is equipped with two mechanisms: the provision of hospice palliative care to terminal patients and clarification of the end-of-life care decision-making process. With respect to the former, ELDA declares the right of patients to hospice palliative care and the responsibility of healthcare providers and states to provide it. With respect to the latter, the legislation provides clinicians and patients with a decision-making framework, as well as the interpretation and application of relevant principles, which can potentially remove the confusion and settle the debate amongst Korean society.

3.3 Characteristics of ELDA¹⁰

3.3.1 Principles of End-of-Life Care and the State's Responsibilities

3.3.1.1 Principles of End-of-Life Care

ELDA emphasises three principles in end-of-life care: human dignity and value, patients' right to know and to self-determination and the duty of medical professionals to provide the best care and information and to

⁹ M.H. Kim, "The Problems and the Improvement Plan of the Hospice/Palliative Care and Dying Patient's Decisions on Life-Sustaining Treatment Act" (2018) 21(1) *Korean Journal of Hospice and Palliative Care* 1.

¹⁰ The English translation of ELDA can be found at: <https://law.go.kr/LSW/lsInfoP.do?lsiSeq=180823&viewCls=engLsInfoR&urlMode=engLsInfoR#0000>. Although this translation originates from a government website, it is not considered an official or legally

respect a patient's decision (Article 3 of ELDA). Whilst the language of the law has raised awareness of the concept of autonomy amongst patients and practitioners, the culture (and even the interpretation of the law) generally continues to place the best interests of the patient first. The tension between autonomy and best interests appears to have been dealt with by placing limits on autonomy and the scope of the right to refuse treatment.

3.3.1.2 State's Responsibility to Improve Quality of End-of-Life Care

There have long been concerns about the poor quality of death amongst Koreans, with most commentary suggesting palliative care as an alternative. However, palliative care had remained only an ideal, not everyday practice, for several reasons, not least the fear that recommending hospice care constituted a recognition of failure by physicians and the abandonment of patients.¹¹ What was notable for Korean legislation was that the opponents of ELDA argued that good hospice care should precede end-of-life decision legislation.¹² It was partly as a result of that argument that the legislative strategy of merging the hospice palliative care bill with ELDA surfaced in the last phase of parliamentary review.

ELDA provides a justification for the state to operate nationwide hospice palliative care (which had in fact been part of the state's responsibility since 2005, as defined by the National Cancer Control Act). It mandates that the state establish a discussion body (the National Hospice and Palliative Care Committee) and submit and implement a national plan (General Plan for Hospice and the Provision and Withdrawal of Life-Sustaining Treatment) (Article 8 of ELDA). The new legislation authorises the Ministry of Health and Welfare to plan and implement programmes. To a certain extent, ELDA can be seen as an extension of hospice palliative care to disease categories other than cancer, as well as a clarification of the Government's authority to set standards for and support hospice palliative care providers.

binding translation. The author has used terms from the translation in this chapter, although he does not agree with the choice of words in all cases.

¹¹ D.H. Moon et al., "Doctor's Attitudes toward Hospice and Palliative Care for Terminal Cancer Patients" (2006) 9(2) *Korean Journal of Hospice and Palliative Care* 93.

¹² Y.H. Ji, "The Catholic Church's Statement on the End of Life Decision Act Bill" (2014) 57 *Hospice* 2, www.koreascience.or.kr/article/JAKO201467958869374.page.

3.3.2 *Scope of the Application*

Article 2 of ELDA provides definitions and defines the subjects of application. Interestingly, the law distinguishes the *terminal* stage of disease from the *dying* stage and *terminal* patients from *dying* patients. A “terminal patient” is defined in Article 2 as

a patient who has been diagnosed as expected to die within a few months [by] the doctor in charge and one medical specialist in the relevant field in accordance with the procedures and guidelines prescribed by Ordinance of the Ministry of Health and Welfare, because there is no possibility of a fundamental recovery, and the symptoms [will] gradually worsen despite proactive treatment.

He or she is also regarded as a potential hospice palliative care beneficiary, but one who is unable to elect the termination of LST. The article originally listed four diseases as terminal illnesses: cancer, AIDS, chronic obstructive pulmonary disease and chronic liver cirrhosis. However, other diseases were added by ordinance of the Ministry of Health and Welfare following the 2018 revision. Patients at the dying stage, or in the “end-of-life process”, are defined as in “a state of imminent death, in which there is no possibility of revitalisation or recovery despite treatment, and [whose] symptoms [are] worsen[ing] rapidly” (Article 2 of ELDA).

Article 2 of ELDA also originally limited the potential LSTs that could be foregone to four specific medical interventions: CPR, haemodialysis, anticancer chemotherapy and artificial ventilation care. This narrow definition was designed as a safeguard against the possible hasty withdrawal of LST but was criticised for ignoring clinical realities. It was thus subsequently revised to include (i) extracorporeal life support, (ii) transfusions, (iii) the infusion of hypertensors and (iv) any procedures medically assessed by the physician to be withheld or withdrawn in the patient’s best interests. It can thus be seen that the legislative approach moved away from narrow definitions towards leaving the determination of whether a given treatment constitutes a *futile* LST to clinical judgement. As for how such judgement should be exercised, there is published professional guidance that suggests, for example, how a patient’s vital signs should be interpreted. This approach demonstrates an understanding that not everything can be specified by law, and hence that the application of the law should be left to professional guidelines.

3.3.3 *Institutionalisation of End-of-Life Care Decisions*

According to ELDA, the state can establish several institutions to support the making and executing of end-of-life decisions on LST. Three official institutions have accordingly been established: the National Agency for the Management of Life-Sustaining Treatment (established under Article 9), the Agency for the Registration of Advance Statements for Life-Sustaining Treatment (ARAS) (established under Article 11) and Institutional Ethics Committees (IECs) (established under Article 14).

The National Agency operates the national end-of-life infrastructure, provides certified education and handles public relations. It works as a national AD registry, identifying and confirming LST plans (LSTPs) and ADs, and is accountable for producing and managing databases of ADs for LST, which cover both AD and LSTP registries. The National Agency also provides research and statistical information on end-of-life decision-making and the execution thereof and is responsible for granting licences to institutions such as hospitals to become registering institutions.

ARAS oversees the private and public institutions that are the focal point of end-of-life decision-making services for the public. These institutions, which can be healthcare institutions, public health centres or qualified non-governmental organisations, provide information to patients (see Section 3.4.2 for further details) and transfer the documents that patients create.

Finally, IECs have similar functions to clinical ethics committees. Their various functions include (i) deliberation (including the review of consulting requests from patients and physicians and requests to change the attending physician) and the review of ADs (although they do not decide on them); (ii) the education of professionals; and (iii) reporting and referral to the National Agency. Physicians may also consult an IEC on a particular prognosis or to seek legal clarification. Whilst IEC recommendations carry some weight, they are not technically binding. In light of the IECs' wide range of functions, they are expected to become the focal point of reporting and communication with the National Agency.

3.4 Application of ELDA

ELDA provides for two processes relating to end-of-life decision-making, which will be referred to here as LSTPs and Advance Statements for LST

(ASLSTs). The Act requires that a patient be in the “dying stage” before his or her decision regarding LST under either an LSTP or ASLST can be executed. Although a patient’s decision on LST under a physician’s order for LST (Physician Order for Life-Sustaining Treatment, POLST) is binding, decisions under a valid ASLST represent only the patient’s (explicit) preferences and are not binding until and unless the ASLST is verified. The two processes are discussed in further detail next.

3.4.1 *Life-Sustaining Treatment Plans*

According to Article 10 of ELDA, an end-of-life care plan takes the form of an LSTP. Under this regime, a doctor may supply the patient with the information required to prepare a plan to terminate LST or, at the patient’s request, prepare an LST plan for a terminal patient at a medical institution. Although the process can be initiated by a patient or the doctor in charge, physicians are seen as playing the leading role.

The process of preparing an LSTP under ELDA is akin to advance care planning, but is limited to LST during a terminal patient’s last days of life. The patient may in his or her LSTP specify matters relating to the termination of LST, as well as matters concerning the use of hospice care (Article 10(4) of ELDA). As safeguards, Article 10 of ELDA prescribes formalities for LSTPs and provides requirements for the registration of POLSTs at a medical institution, record-keeping and notification of the National Agency.

3.4.2 *Advance Statement for Life-Sustaining Treatment*

In Korea, an ASLST can be viewed only as evidence of a person’s preferences regarding LST until and unless it has been verified, as discussed in further detail later. At the point of verification, it becomes binding on the doctor. An ASLST is a document similar to a living will. It is written when a person is relatively healthy and independent. It contains the person’s decisions regarding (i) the termination of LST and (ii) the use of hospice care where necessary (Article 12 of ELDA). There are no legal requirements in relation to either witnessing or how the person’s mental capacity is to be assessed. ELDA does, however, mandate that personnel from the registering institution meet with the person to confirm that he or she understands the following matters before the ASLST can be considered valid.

- i. Matters concerning the methods of implementing LST and making a decision to terminate such treatment.
- ii. Matters concerning selecting and using hospice care.
- iii. Matters concerning the validity and invalidity of ASLSTs.
- iv. Matters concerning the preparation, registration, keeping and notification of ASLSTs.
- v. Matters concerning amending and withdrawing ASLSTs and subsequent measures.
- vi. Other matters prescribed by ordinance of the Ministry of Health and Welfare.

The definition of registering institutions is construed narrowly under Article 11(1) of ELDA as a safeguard, limiting them to regional healthcare institutions under the Regional Public Health Act; medical institutions; public institutions under the Act on the Management of Public Institutions; and non-profit corporations registered with the Government that have the proper qualifications and trained personnel to provide services related to ASLSTs. Although registering institutions must be licensed, their personnel need not be medically or legally trained and may be representatives of the medical institution concerned or even volunteers. As they may have only a basic understanding of ASLSTs, it is not uncommon for the assessment of whether a person is mentally capable of making an ASLST to be left to the institution's nurses or volunteers. After the ASLST is prepared, it has to be registered and kept at the registering institution (Article 12(4) of ELDA), and the National Agency must be notified of the registration (Article 12(5) of ELDA). Licensed healthcare professionals will then be able to access this ASLST when a decision regarding the use of LST or hospice care needs to be made.

As noted, although a registered ASLST is valid under ELDA, it can serve only as evidence regarding the patient's LST preferences. For an ASLST to be binding, the doctor must verify the patient's intentions with him or her when the ASLST is retrieved for use (Article 15 of ELDA). When the patient is in the "end-of-life process" but is still of sound mind, the requirement to verify the patient's intentions does not pose much of a hurdle. In situations where the patient becomes incapacitated and is unable to verify the ASLST, however, the doctor needs to obtain the agreement of a second doctor (Article 17 of ELDA), and during this confirmation the doctors typically have a discussion with the family about the authenticity of the document. An additional complexity arises when a patient in the "dying stage" becomes incapacitated and has no ASLST. The current law

does not provide for the designation of a proxy for LST-related decision-making, although it is worded such that the patient's family members can bear witness to his or her LST preferences, which means that they are effectively able to make LST-related decisions on behalf of the patient in the event of incapacity. In such a situation, the doctor will consult with family members, and if they unanimously bear witness to a consistent expression of the patient's preference, then that preference will be regarded as the patient's will (in other words, his or her presumed will), and the doctor will need to follow it (Article 17, Clause 2 of ELDA).

3.4.3 *LSTPs versus ASLSTs*

There are thus two legal mechanisms by which individuals can indicate their preferences in relation to LST under ELDA, with LSTPs having priority over ASLSTs. That priority explains much of the confusion surrounding the force and application of ASLSTs. If an LSTP is made, any ASLST made prior to it becomes invalid. There are also many more hurdles to overcome before an ASLST can be made and/or implemented, including confirmation of the six matters listed previously and verification of the patient's intentions (where the patient is capacitous), which reflects a rather reserved attitude towards ASLSTs.

There have been attempts to give more weight to ASLSTs, but there seems to be no appeal in legislation. In fact, the original objective was for LSTPs to support the implementation of ASLSTs, with an AD being a small but important component of giving a patient full control over a key decision within the larger process of planning his or her end-of-life care. However, that objective appears to have been lost in the legislative process. ASLSTs have yet to move past being an overarching statement of patient preferences that assists physicians in deciding on the use of LST. We will likely have to wait for another legislative opportunity for ASLSTs to reach their full potential. In the meantime, it is likely that they will remain marginalised or perhaps become even further marginalised given the reality of decision-making by patients and families in the Korean context, as we will see in the following section.

3.5 End-of-Life Decision-Making in Practice

3.5.1 *Low Utilisation Rate*

Equipping patients with the power to decide what end-of-life care, LST in particular, best suits them is closely tied to the general well-being of

the population. Such end-of-life decision-making mechanisms as LSTPs and ASLSTs enable patients to communicate their preferences regarding the use of LST and hospice care, allowing sufficient planning for a death with dignity and reducing the need for futile LST. However, as of January 2020, 85,076 LST decisions (LSTD) had been implemented, with the number of decisions made through family statements or agreements (55,775) nearly twice as high as the number made using an LSTP or ASLST (29,301). The LSTD system thus appears to be based on family decisions, which may or may not be based on patients' preferences or wishes, rather than on direct records of those preferences/wishes, and less than 20 per cent of dying people seem to be benefiting from the legislation. One potential reason is the age and health status of those who currently make an AD, and the situation should improve as awareness of AD use grows and more healthcare professionals gain experience and knowledge of using ADs for end-of-life decision-making. Other reasons for the low utilisation rate of LSTPs and ASLSTs may be linked to the sociocultural context of Korea, which is explored in further detail next.

3.5.2 *Sociocultural Context*

The two key sociocultural factors that play an important role in end-of-life decision-making in Korea are the role of the family and the role of Confucian values.

In relation to first factor, as in other Asian countries, the life of the individual in Korea is strongly tied to the family. Individuals live for the family and by its support. The dignity of the individual is seen to come from the family, especially from generational relations. Accordingly, decisions regarding end-of-life care tend to be taken collectively. A study of end-of-life communication amongst elderly Koreans found that less than 20 per cent of patients prefer making treatment decisions alone,¹³ with over 90 per cent of cancer patients and their caregivers preferring family involvement in treatment decision-making.¹⁴ Family members do not perceive their involvement as infringing the patient's autonomy, but rather as a means to show support and alleviate the

¹³ D.W. Shin et al., "End-of-Life Communication in Korean Older Adults: With Focus on Advance Care Planning and Advance Directives" (2016) 16(4) *Geriatrics Gerontology International* 407, 412 (footnote 46).

¹⁴ *Ibid.*, footnote 45.

patient's burden.¹⁵ There is thus less emphasis on the individual in end-of-life decision-making in Korea than in the West: patients generally do not express their preferences for a given treatment, and the family can be expected to take an active role¹⁶ or even decide on the patient's behalf when it comes to life/death decisions.^{17,18}

In relation to the second factor, the current underutilisation of LSTPs and ASLSTs reflects the ethos of a traditionally Confucian society such as Korea,¹⁹ particularly with respect to the elderly. Confucian values dictate that the care of elderly parents is the duty of children,²⁰ and the elderly are, in turn, often dependent – financially and physically – on their children for healthcare and are expected to follow the decision of the family, particularly with respect to decisions pertaining to such value-laden issues as birth, marriage and death. The concept of *Hyo* (meaning filial piety) is also a cardinal Confucian virtue that plays a role in end-of-life decision-making. For example, it is common for children to feel obliged to continue LST for their family members because they equate providing medical treatment with being filial.²¹ Furthermore, filial piety requires children to keep their parents comfortable for as long as possible. As many Koreans consider knowledge of a poor prognosis to be painful and even unbearable, information relating to their condition is often concealed from patients until the very end of their illness trajectory.²²

¹⁵ D.W. Shin et al., “Preferences for and Experiences of Family Involvement in Cancer Treatment Decision-Making: Patient-Caregiver Dyads Study” (2013) 22 *Psycho-Oncology* 2624, 2628 (footnote 22).

¹⁶ *Ibid.*, p. 2624 (footnotes 1, 2).

¹⁷ Ministry of Health and Welfare, “End of Life Care Consultation Guidelines for Healthcare Professionals” [in Korean] (2020), www.lst.go.kr/comm/referenceDetail.do?pgNo=1&cate=&searchOption=0&searchText=&bno=1970.

¹⁸ S.Y. Park et al., “A National Study of Life-Sustaining Treatments in South Korea: What Factors Affect Decision-Making?” (2021) 53(2) *Cancer Research and Treatment* 593.

¹⁹ I. Lee, “Filial Duty as the Moral Foundation of Caring for the Elderly: Its Possibility and Limitations”, in R. Fan (ed.), *Family-Oriented Informed Consent: East Asian and American Perspectives* (Cham: Springer International Publishing, 2015), 137–47, https://doi.org/10.1007/978-3-319-12120-8_9.

²⁰ *Ibid.*

²¹ S. H. Kim, “Family Surrogates’ Decision Regret and Psychological Stress about End-of-Life Cancer Treatments: Path Analysis” (2018) 48(5) *Journal of Korean Academy of Nursing* 578, <https://doi.org/10.4040/jkan.2018.48.5.578>.

²² See, for example, S.Y. Park et al., “End-of-Life Care in ICUs in East Asia: A Comparison among China, Korea and Japan” (2018) 46(7) *Critical Care Medicine* 1114, 1121 (footnote 22), which discusses the concealing of information from terminally ill patients and the reasons for doing so, and D.Y. Oh et al., “Discrepancies among Patients, Family Members, and Physicians in Korea in Terms of Values Regarding the Withholding of

Given that research demonstrates a strong association between a patient's understanding of his or her condition and his or her preference for making an AD,²³ such concealment of information likely contributes to the low utilisation rate of LSTPs and ASLSTs.

3.6 The Way Forward

In considering the way forward for Korea, we need to address some of the concerns with the current legislation.

3.6.1 *Limited Autonomy*

Although patients have opportunities to express their preferences to the people who care for them, such as their doctors, family members and other caregivers, the current law may limit their ability to exercise their autonomy, for example, by viewing an ASLST only as evidence of a person's preferences rather than a binding statement and permitting surrogate decision-making by family members when the person is incapacitated. The result could well be too much emphasis on the family's opinion at the expense of the patient's. In addition to the risk of family members misinterpreting patients' preferences, there is also the possibility of family members putting forth statements contrary to the ASLST if they do not agree with it and the patient is incapacitated. Revising ELDA in such a way that a valid ASLST always trumps the family's decision-making authority would be one way to ensure that patients' autonomy is strengthened in incapacitation scenarios.

In addition, the scope of ELDA's application is overly narrow. For example, it applies only after a patient's condition has been confirmed by two physicians to be irreversible and not responsive to treatment. Moreover, there are just four types of LSTs that can be withdrawn, namely, CPR, haemodialysis, the administration of anticancer drugs and mechanical ventilation (Article 2 of ELDA). These restrictions leave little space for patients' preferences to be afforded much significance.

Treatment from Patients with Terminal Malignancies" (2004) 100(9) *Cancer* 1961, 1965, a study in which it was found that only 26 per cent of patients in the sample understood their disease progression and that less than half of cancer patients already in an advanced stage accurately understood their illness.

²³ S.H. Yoo et al., "Association of Illness Understanding with Advance Care Planning and End-of-Life Care Preferences for Advanced Cancer Patients and Their Family Members" (2020) 28 *Supportive Care in Cancer* 2959, 2961.

3.6.2 *ELDA's Inability to Reflect Societal Changes*

ELDA adopts a narrow definition of “family members”, requiring them to be of the same bloodline (lineal ascendants, descendants and siblings) as the patient with the single exception of the patient’s spouse. In reality, not only are unregistered partnerships on the rise in Korea, but indirect family members (e.g. nieces and nephews) are also increasingly becoming patients’ primary or sole caregivers. As discussed previously, family members have a role in bearing witness to the patient’s preferences regarding LST, and, under the current legislation, that role is limited to family members as narrowly defined in ELDA to the exclusion of other caregivers who might be better able to offer evidence of those preferences. Furthermore, recent studies have shown a decrease in the younger generation’s perceived duty to take care of elderly parents.²⁴ This shift in perceived responsibility and levels of involvement may also affect the feasibility of verifying a patient’s preferences through their family members. To adapt to Korea’s changing needs, it is worth considering whether ASLSTs could be implemented without further verification, particularly given that there are already procedures in place to confirm a patient’s understanding prior to the making of an ASLST.

In terms of the way forward, patient empowerment should be the first priority. The current legislative framework permits too large a role for the family in end-of-life decision-making. This is not to say that the family should not be engaged in the process at all, but rather that enabling patients to exercise their right to know and have their preferences respected should come first. From a legislative point of view, ELDA currently leaves many matters relating to ASLST validation open ended, and the legislative framework would thus benefit from a more systematic, well-planned validation process for ADs.²⁵

²⁴ H.K. Kim, C.M. Park and K. Nakajima, “A Study on the Perception of Social Care for the Elderly: Comparison Analysis between College Students and their Parents Group” (2010) 30(1) *Health and Social Welfare Review* 170; Ministry of Health and Welfare, “Report of the Survey of Living Conditions and Welfare Needs of Korean Older Persons” (2020), www.mohw.go.kr/react/jb/sjb030301vw.jsp?PAR_MENU_ID=03&MENU_ID=032901&CONT_SEQ=366496, p. 254.

²⁵ Despite the lack of a systematic process, there is in fact little room for ambiguity in current ASLST implementation owing to the limited scope of ASLST application. As discussed previously, ASLSTs apply only in the patient’s last days during the “end-of-life process”. Where treatment is deemed futile at that stage, there is little left to be determined, and the patient will likely pass away soon after.

3.7 Conclusion

ELDA is the result of experience and a painstaking consensus-building process, although the law is narrow in application and areas for improvement remain. What Korean society has agreed is that every dying patient deserves respect and humane care and that such care is something that society should provide. As with other social institutions, however, ELDA and related social institutions need further improvement, particularly with regard to the scope and application of ADs. Accordingly, continued discussion of ELDA and the implementation of end-of-life decision-making tools is necessary. Respectful communication and collaboration amongst all relevant stakeholders will be necessary to balance the opinions of the public with empowering patients in the end-of-life decision-making process.